*Saving lives through education, advances in treatment, and finding a cure for Barth syndrome.*

**Devin (age 12)**

*(Photo courtesy of Tiffini Allen 2016)*

# Barth Syndrome Foundation Annual Report 2016

# Dear BSF Friends,

Lindsay Groff

Devin, the handsome young man on the cover of this report, celebrated his twelfth birthday at our conference back in June. What a special night it was. As we all sang happy birthday and enjoyed the delicious cake, I glanced over at Devin's mom, Nicole. The look on her face said so much without her saying a single word. She was looking at her son, surrounded by other boys just like him… in a place without judgement for looking small for his age, a room filled with love and hope. And for that moment, Devin was just like everyone else. What a moment of joy that was not just for Devin and his mom, but for all the moms and dads, siblings, grandparents, scientists, doctors, and friends.

While you may not have been there in person, you were there in spirit. Without your gifts, the conference would not be possible. Your support brought hope to our families as they listened intently in their sessions. Your donations allowed the top researchers and clinicians to discuss groundbreaking ideas.

In addition to another truly inspiring conference, 2016 brought other exciting accomplishments. Thanks to you, the Barth Syndrome Foundation (BSF) celebrates another year of progress and hope. Here are some highlights you'll read about in this report:

- Adorable Wyatt dropped the puck at a New York Islanders game, raising awareness to a huge audience of hockey fans across the US.
- Dr. Michael Schlame was awarded the prestigious Varner Award for his selfless support over many years and received a second R01 grant from the National Institutes of Health (NIH).
- Devin's mom, Nicole, talks about their journey with Barth syndrome.
- Dr. Michael Chin received an R01 grant from the NIH, building on seed funding from BSF.
- Four worthy grants received funding to push research further, thanks to your generosity.
- BSF remains in a strong and healthy financial position.

You give us hope. Thank you for all you do and thanks for making 2016 another fantastic year.

With pride and gratitude,

*Lindsay B. Groff*

Lindsay B. Groff
Executive Director

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Dr. Iris Gonzalez & Henry (age 8)

# Dear Friends,

Marc Sernel

I am delighted to report that 2016 was yet another strong year for the Barth Syndrome Foundation (BSF). Thanks to your incredible generosity, we have accomplished so much.

BSF advanced the mission through increasing awareness and funding innovative research about Barth syndrome, as you'll read about in the following pages.

We also continue to make great progress with both foundational research and in moving toward possible clinical trials with not just one but several potential therapeutic candidates (see, *e.g.*, page 8 for this year's research grants). All of the work done over the past 16 years has placed us at the point of transformative breakthroughs.

We anticipate that BSF will face new and greater challenges as we continue to push hard for a treatment or cure for Barth syndrome. Taking the next steps from promising therapeutic possibilities to actual clinical trials to available treatments will require even more work, sacrifices, and resources than those we have expended to date. Thus, while I am happy about our achievements in 2016 and thankful to all that contributed to our successes, I am also deeply aware of the challenges that lie ahead between us and our ultimate goals. I can assure you that BSF will not give up. We will continue our quest to end the suffering caused by Barth syndrome.

Thank you all for your continued support in this journey.

*Marc Sernel*

Marc Sernel
Chairman

# December 2016: Barth syndrome by the numbers

| | |
|---|---|
| Known individuals living with Barth syndrome | **211** in **26** countries |
| Number of genetically confirmed individuals enrolled in Barth Syndrome Registry 2.0 | **54** |
| Grant awards funded since BSF was established | **99** totaling **$4.2 million** |
| Percentage of BSF Staff and Board members who donated in 2016 | **100%** |

**"The Barth Syndrome Foundation community is tight-knit, knowledgeable, and inclusive. The Foundation includes not only the patients and their families but also scientists, physicians, and others taking care of Barth patients, all working together — and I mean really together — to cure Barth syndrome. I believe the single "jewel" that epitomizes this Foundation is the biennial international conference they organize, which brings together patients, their families, and scientists from around the world to make headway into this devastating disease."** ~ *Colin Steward, PhD, FRCP, FRCPCH, Bristol Royal Hospital for Children, England*

# Awareness/Education/Support

**"I've been involved with BSF for about 10 years now and I can't speak highly enough of this great organization. For a small group focused on a rare genetic condition, it's amazing to see the impact they have. The Foundation has raised millions of dollars for research into Barth syndrome, has raised awareness among the medical community and is always there for parents in need."** *~ BSF Board Member*

## Extending Our Voice Globally

Families enjoying the Australian Family Outreach

### Australian Family Gathering

Dr. Matt Toth, BSF Science Director, and Shelley Bowen, Director, BSF Family Services & Awareness, joined the Australian families, via GoToMeeting, during their Australian family gathering in Melbourne Australia in March, 2016. Matt provided the families with an overview about potential therapies in the pipeline and answered questions the Australian families had about opportunities to participate in these studies. *(Photo courtesy of Mel [2016])*

## Barth Syndrome Represented at New York Islanders Game

Wyatt did the puck drop
and appeared on the Jumbotron

In December, 2016, the New York Islanders held a "Barth Syndrome Night", and allowed us to raise awareness and money for our cause. Nine-year-old, Wyatt, appeared on the Jumbotron, rode the Zamboni, high-fived all the players, got an official jersey, and even did the puck drop!

*(Left photo courtesy of New York Islanders; right photo courtesy of BSF [2016])*

'Donations please!'
Volunteers at New York Islander Game

## Advancing Diagnosis

BSF published a revised and informative brochure about Barth syndrome, written by people at BSF and reviewed by the clinical members of our international Scientific and Medical Advisory Board (SMAB). It provides a good overview of this complicated syndrome from several angles. One important section lists a summary of some of the unusual clinical complexities that can arise (sometimes very quickly) as a result of the multi-system nature of this disorder. This brochure is free and available online at www.barthsyndrome.org. The purpose is to promote early, accurate diagnosis and appropriate treatment for patients.

**"I'm quite certain Barth syndrome is under-diagnosed. If you have never heard of the disease, you are not going to look, you are not going to find."** *~ Jeffrey Towbin, MD, Co-Director, Heart Institute, Le Bonheur Children's Hospital; Chief of Cardiology, St. Jude Children's Research Hospital; Chief of Pediatric Cardiology, University of Tennessee Health Science Center, Memphis, TN; Barth Syndrome Foundation Scientific & Medical Advisory Board*

# Conference

The 2016 Barth Syndrome Foundation (BSF) International Scientific, Medical & Family Conference was remarkable. The motto for the conference, "Team Barth," brought into focus what this new frontier of clinical trials/studies will mean for Barth syndrome individuals, their families, and the researchers and clinicians who attended. Like previous conferences, the 2016 meeting provided information for new and for experienced families, collected new scientific/clinical information, and offered valuable training/lifestyle tips.

The Scientific and Medical sessions showcased the incredible scientific progress in understanding Barth syndrome and outlined the therapeutic ideas and therapies that have germinated with BSF's support over the years. The BSF community is now at the stage where Barth syndrome individuals need to volunteer for clinical studies and clinical trials to reach our common goal, treatments and a cure. It will certainly take a "team effort" to reach this "final frontier" that we believed would come one day.

Our mission has always been the compass to guide us. When Kate McCurdy (a member of BSF's Scientific and Medical Advisory Board) pointed to the midpoint of a clinical trial roadmap during her presentation to the families, our families gained a clear view of the progress we have made since 2000. There is more ground to cover, but the energy in the room strengthened as researcher after researcher presented opportunities about potential therapies for BTHS. No longer is the brass ring of Barth syndrome therapies a distant dream but is realistically within our grasp. We have always had hope that we would someday reach our ultimate vision of ending suffering and death caused by Barth syndrome. With clinical trials in the pipeline, that hope may well become a reality in the not-so-distant future. Every attendee, regardless of role or relationship who had ever attended a previous conference hailed the 2016 conference as the best one ever. Every first-time family attendee overwhelmingly found the conference to be transformational.

Attendees of BSF's 2016 conference *(Photo courtesy of Amanda Clark [2016])*

## Paula & Woody Varner Award for Pioneers in Science and Medicine

The Varner Award for Pioneers in Science and Medicine was presented to Dr. Michael Schlame, MD, Associate Professor of Anesthesiology & Cell Biology, New York University School of Medicine; Director, Cardiothoracic Anesthesia, New York University Langone Medical Center, New York, NY, who currently chairs the Barth Syndrome Foundation's (BSF) international Scientific and Medical Advisory Board.

Dr. Schlame was the first person to receive a R01 research grant specifically on Barth syndrome. An R01 is a major, highly competitive grant from the National Institutes of Health, and he received a second R01 award in 2016. He has published many of his research findings on Barth syndrome in top scientific and medical journals. In addition to his own scientific research, Dr. Schlame's clinical expertise in anesthesiology and intensive care have also contributed to the care of Barth syndrome patients. Dr. Schlame also has contributed significantly to the work of BSF by spreading the word about Barth syndrome far and wide.


[L-R] John (age 35) & Dr. Michael Schlame
*(Photo courtesy of BSF [2016])*

# Family Services

**"Thanks to BSF, we are not on this journey alone. Expertise is always an email or phone call away. Attending BSF's conference enables us to learn so much about this incredibly rare condition, while spending time with families from around the world that are just like Devin."** ~ *Nicole, Mother of Nathaniel & Devin, Michigan*

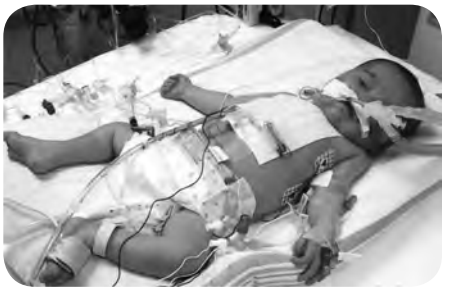
## Meet Nathaniel & Devin

Nathaniel
*(Photo courtesy Nicole)*

My first son, Nathaniel Joseph, died when he was two weeks old. I had no idea he was sick. My world was turned upside down. At that time, I didn't know about Barth syndrome.

Our journey began in 2002. When Nathaniel Joseph was born on September 9th, he seemed to be the picture of health. That is, until he died unexpectedly two weeks later. The cause of death was eventually determined to be dilated cardiomyopathy. We were told it was a fluke, a one in a billion thing. Nothing could have been done, and it would never happen again.

When I discovered I was pregnant again, just over a year later, I panicked. Numerous tests were performed throughout the pregnancy, and I was assured my baby had a healthy heart. However, when Devin James was born on July 22, 2004, he couldn't breathe. He was rushed to the neonatal intensive care unit, where an X-ray revealed a severely enlarged heart. He was intubated and airlifted to our local children's hospital. I was terrified. I just couldn't bear the thought of losing another child.



Devin
*(Photo courtesy of Nicole)*

Devin spent nine agonizing weeks in the pediatric intensive care unit, where he suffered complete heart failure and a full cardiac arrest. Eventually, my sweet baby underwent successful heart transplant surgery.

Barth syndrome had been suspected early on, but genetic testing performed prior to the transplant revealed a mutation that had never been seen. Although Devin's symptoms and family history indicated Barth syndrome, it was not considered enough for a diagnosis.

In 2006, I saw an episode of Discovery Health Channel's "Mystery Diagnosis" that featured Barth syndrome. I immediately got in contact with Shelley Bowen (Director, BSF Family Services & Awareness). She urged me to look further into genetic testing.

After six months of additional testing, Devin was finally diagnosed with Barth syndrome at the age of 27 months, more than two years after receiving the "gift of life," and four years after the death of his brother, Nathaniel.

Devin (age 10)
*(Photo courtesy of Amanda Clark 2016)*

This diagnosis is so important in many aspects of Devin's care, including nutrition, metabolism, growth, cardiac care, physical therapies, education, and more. Infection is a constant worry. We once spent four days in hospital for a scraped elbow! Devin takes countless medicines and supplements. We know the emergency room all too well. Life can be hard as a 12-year-old boy who is the size of most seven-year-olds. Add the suffering from muscle weakness, extreme fatigue, and lots of missed school – it just breaks my heart some times. As his mother, I worry constantly.

One light in this darkness is the Barth Syndrome Foundation (BSF). Thanks to BSF, we are not on this journey alone. Expertise is always an email or phone call away. Attending BSF's conference enables us to learn so much about this incredibly rare condition, while spending time with families from around the world that are just like Devin.

Devin is also seen at the Barth Syndrome Clinic at Kennedy Kreiger Institute, the only clinic in the US that specializes in Barth syndrome. And, we are very excited about clinical trials on the horizon for the first ever, possible treatment of Barth syndrome!

Thanks to BSF and the "gift of life," I am the proud mother of a relatively healthy and happy 12-year-old boy. I am so grateful to all the donors who make the work of the foundation possible. Thank you for helping Devin and all of his "Barth brothers" around the world.

# Science & Medicine

## BSF "Seed Funding" Leads to National Institute for General Medical Sciences Grant

Dr. Michael Chin

Barth syndrome researcher, Michael Chin MD, PhD, Associate Professor, University of Washington, Seattle, WA, was awarded an R01 grant from the National Institute for General Medical Sciences for his proposal entitled "Intracellular mitochondrial enzyme replacement therapy for heart and skeletal muscle in Barth syndrome." This grant will enable Dr. Chin to continue the work that he began with initial funding from the Barth Syndrome Foundation. He will study the mechanism by which recombinant *tafazzin* enters the cells and travels to the mitochondria, measure the pharmacokinetics and tissue distribution of the enzyme replacement therapy, and measure effectiveness of the enzyme replacement therapy in correcting cardiomyopathy, skeletal myopathy and neutropenia in a mouse model of Barth syndrome.

Dr. Chin practices general adult cardiology at the University of Washington Medical Center. He directs a research laboratory focused on understanding the molecular biology of the cardiovascular system. His major research interests include understanding transcriptional control of cardiovascular development, the environment influences that affect the development of cardiovascular disease and developing novel therapies for cardiovascular and myopathic disorders. Dr. Chin was awarded the following research grants from BSF entitled "Enzyme replacement therapy in heart failure associated with *tafazzin* deficiency" (2014), "*Tafazzin* enzyme replacement therapy in a mouse model of Barth syndrome" (2013), and "*Tafazzin* enzyme replacement therapy for heart muscle in Barth syndrome" (2012). *(Photo courtesy of Dr. Michael Chin [2016])*

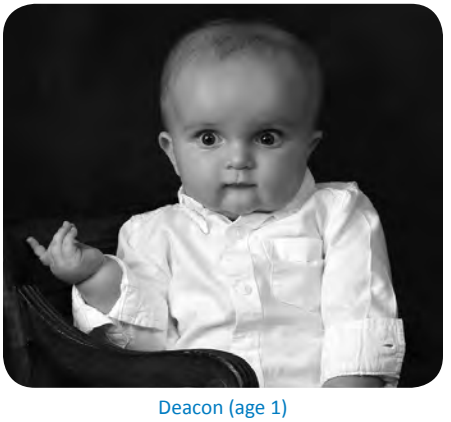
## BSF Researcher Awarded R01 Grant from the National Institute of General Medical Sciences

Dr. Michael Schlame

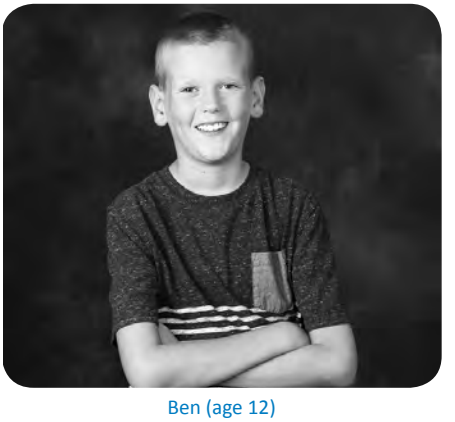
Barth syndrome researcher, Michael Schlame, MD, Associate Professor, New York University School of Medicine, New York, NY, was awarded an R01 grant from the National Institute for General Medical Sciences for his proposal entitled "Abberant cardiolipin dynamics in Barth syndrome." The objective of this application is to identify the mechanism that causes partial replacement of cardiolipin by monolyso-cardiolipin in Barth syndrome and to elucidate its functional consequences. This objective fits into our broad goals to understand the function of cardiolipin in mitochondria and to unravel the molecular pathophysiology of Barth syndrome.

Dr. Schlame´s subspecialties include cardiothoracic anesthesiology and critical care, and his research interests include Barth syndrome, lipids and mitochondria (with particular concentration on mitochondrial energy metabolism), pulmonary surfactant, cardiolipin, mechanisms of multiple organ failure, and cardiomyopathy. His clinical focus includes adult and pediatric critical care, cardiothoracic anesthesia, and pediatric anesthesia.

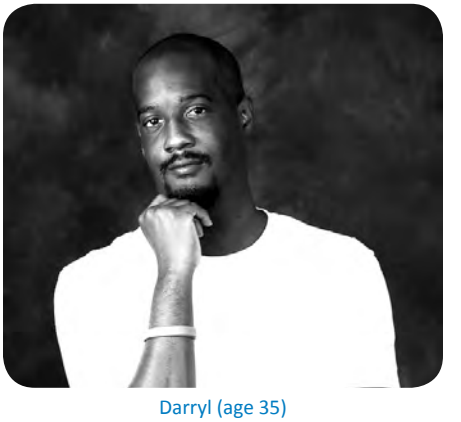
Dr. Schlame is also chair of the Barth Syndrome Foundation's international Scientific and Medical Advisory Board. *(Photo courtesy of Amanda Clark [2016])*



Deacon (age 1)



Ben (age 12)



Darryl (age 35)

*(Photos courtesy of Amanda Clark [2016])*

# Science & Medicine

## Research Grant Program

With the completion of the 2016 Barth Syndrome Foundation (BSF) Research Grant Cycle, 15 annual award cycles have committed a total of US $4.2 million to this important effort through 99 research grants to 58 principal investigators around the world. As with all BSF grant cycles, the projects from the 2016 cycle that were accepted by BSF were actually awarded the following year, thus being included in 2017 fiscal year expenses. BSF, with the advice of its international Scientific and Medical Advisory Board, and with support from international affiliates, awarded four research projects. BSF is very happy to be able to support the following grant recipients:

| | |
|---|---|
|  | **Christina Pacak, PhD**, Assistant Professor, University of Florida, Gainesville, Florida<br><br>"Optimization of AAV-mediated gene therapy for Barth syndrome"<br><br>Award: US $100,000 over 2-year period<br><br>**Funding for this award was provided by the Will McCurdy Fund for Advancement in Therapies for Barth Syndrome and Barth Syndrome Foundation of Canada* |
| | |
|  | **Deborah Tribouillard-Tanvier, PhD**, Permanent Researcher, CNRS, University of Bordeaux, Bordeaux, France<br><br>"Discovery of drug candidates for the Barth syndrome using a yeast-based screening approach and higher eurkaryotic models of this disease"<br><br>Award: US $44,000 over 2-year period<br><br>**Funding for this award was provided by Association Barth France* |
| | |
|  | **W. Todd Cade, PT, PhD**, Professor, Washington University, St. Louis, Missouri<br><br>"Characterization of the 'metabolic phenotype' in Barth syndrome with cardiac transplantation"<br><br>Award: US $49,820 over 1-year period with $21,000 in travel expenses<br><br>**Funding for this award was provided by the Will McCurdy Fund for Advancement in Therapies for Barth Syndrome* |
| | |
|  | **Shanta Dhar, PhD**, Associate Professor, University of Miami Miller School Medicine, Miami, Florida<br><br>"Cardiolipin enhancing biodegradable nanoparticle for Barth syndrome"<br><br>Award: US $50,000 over 2-year period<br><br>**Funding for this award was provided by the Science & Medicine Fund* |

A complete list of all grant awardees can be found on BSF's website at www.barthsyndrome.org.

*(Photos courtesy of grant recipients [2016])*

# Finances

Through YOUR generosity, we funded more ground-breaking scientific research and supported more families in need. We continue to work hard (and smart) to get the best results from our precious resources.

In these pages, you can read about our triumphs in 2016. None of this work would have happened without your help. We are grateful to all those who respond willingly to our request for donations. You are helping us get a little closer to our ultimate vision of a world in which Barth syndrome no longer causes suffering or loss of life.

You can feel confident when making a donation to BSF. Together, the staff and Board ensure that the endorsement of the Better Business Bureau Wise Giving Alliance and the National Health Council continues to be earned. The 20 Standards of Accountability and 43 Standards of Excellence, respectively, are applied to all we do. We have also earned a top rating from Great Nonprofits.

Travis (age 3)
*(Photo courtesy of Amanda Clark 2016)*

## Statement of Financial Position

For year ended December 31, 2016 (with comparative totals for year ended December 31, 2015)

### Assets

| | 12/31/2016 | 12/31/2015 |
|---|---|---|
| **Assets:** | | |
| Cash & cash equivalents | $ 1,188,645 | $ 1,592,360 |
| Investments | 2,584,382 | 2,302,699 |
| Accounts receivable | 7,898 | 2,352 |
| Prepaid expenses | 13,011 | 16,495 |
| **Total assets** | **$ 3,793,936** | **$ 3,913,906** |

### Liabilities and Net Assets

| | 12/31/2016 | 12/31/2015 |
|---|---|---|
| **Liabilities:** | | |
| Accounts payable & accrued expenses | $ 20,904 | $ 16,726 |
| Grants payable | 195,475 | 224,101 |
| **Total liabilities** | **$ 216,379** | **$ 240,827** |
| **NET ASSETS:** | | |
| Unrestricted | $ 918,886 | $ 700,727 |
| Temporarily restricted | 2,658,671 | 2,972,352 |
| **Total net assets** | **$ 3,577,557** | **$ 3,673,079** |
| **Total liabilities & net assets** | **$ 3,793,936** | **$ 3,913,906** |

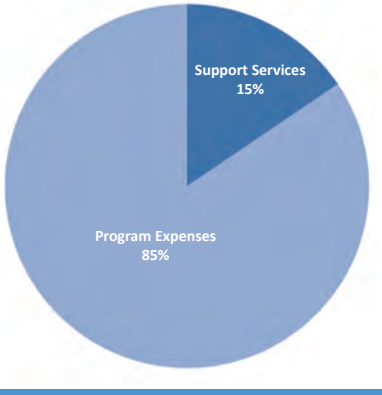
*See annual audit for notes and additional information

## Statement of Activities

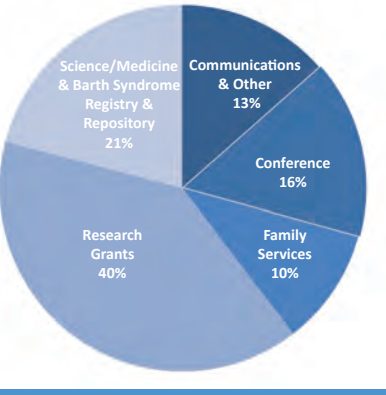
For year ended December 31, 2016 (with comparative totals for year ended December 31, 2015)

| | Year Ended 12/31/2016 | Year Ended 12/31/2015 |
|---|---|---|
| **PUBLIC SUPPORT AND OTHER REVENUES:** | | |
| Public Support: | | |
| Contributions | $ 1,001,616 | $ 3,074,346 |
| Grant Income | 25,000 | 64,475 |
| Interest Income | 55,791 | 26,632 |
| Realized Gain (Loss) on Sale of Stock | (701) | 16,961 |
| Unrealized Gain (Loss) on Investments | 53,582 | (18,072) |
| **Total Public Support & Other Revenues** | **$ 1,135,989** | **$ 3,147,381** |
| **EXPENSES AND LOSSES:** | | |
| Program Services: | | |
| Communications & Other | $ 140,368 | $ 121,864 |
| BSF Conference | 164,146 | 30 |
| Family Services | 107,663 | 126,542 |
| Barth Syndrome Registry & Repository | 20,342 | 23,013 |
| Research Grants | 439,494 | 625,381 |
| Research Grants Funded Directly by BSF Affiliates | (28,846) | (34,917) |
| Science & Medicine | 197,295 | 197,725 |
| | **$ 1,040,462** | **$ 1,059,638** |
| Supporting Services: | | |
| Management & General | $ 110,956 | $ 86,987 |
| Development & Fundraising | 80,093 | 85,685 |
| | **$ 191,049** | **$ 172,672** |
| **Total Expense & Losses** | **$ 1,231,511** | **$ 1,232,310** |
| **CHANGE IN NET ASSETS** | (95,522) | $1,915,071 |
| **NET ASSETS, beginning of year** | $ 3,673,079 | 1,758,008 |
| **NET ASSETS, end of year** | **$ 3,577,557** | **$3,673,079** |

**All Expenses**




**Breakdown of Program Expenses**




Note: BSF's full 2016 audited financials are available on our website at **www.barthsyndrome.org**.

# Leading the Way

The Barth Syndrome Foundation's (BSF) Board of Directors provides oversight of governance, fundraising efforts, and the overall guidance of BSF, while BSF's international Scientific & Medical Advisory Board offers expertise that is invaluable to the mission and future of our organization. Finally, BSF is privileged indeed to have the support of key partners from the public and private communities that provide the bulk of the funding for our programs. BSF wishes to thank and recognize all of the individuals for their hard work and dedication.

| Barth Syndrome Foundation<br>2005 Palmer Avenue #1033, Larchmont, NY 10538 | | |
|---|---|---|
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|---|---|
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| **W. Todd Cade, PT, PhD**; Physical Therapy & Internal Medicine, Washington University School of Medicine, St. Louis, MO | **Mark Tarnopolsky, MD, PhD, FRCP(C)**; Neuromuscular & Neurometabolic Clinic, McMaster University Medical Center, Ontario, Canada |
| **Iris L. Gonzalez, PhD**; Molecular Diagnostics Lab, A. I. DuPont Hospital for Children, Wilmington, DE | **Jeffrey A. Towbin, MD**; Pediatric Cardiology, Cincinnati Children's Hospital, Cincinnati, OH |
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| **Mindong Ren, PhD**; Cell Biology, NYU School of Medicine, New York, NY | |

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| **Barth Syndrome Trust (UK & Europe)**<br>1 The Vikings<br>Romsey, Hampshire S051 5RG, United Kingdom | **Barth Syndrome Foundation of Canada**<br>162 Guelph Street, Suite 115<br>Georgetown, ON L7G 5X7, Canada |
| **Association Barth France**<br>13 rue de la Terrasse<br>92150 Suresnes, France | **Association Barth Italy**<br>Piazza Carrobiolo 5<br>20900 Monza, Italy |

# 2016 Donors

## PAULA & WOODY VARNER FUND

**Angels ($1,000 - $4,999)**

Dillon Foundation
Hixson, Christina
Somers, Peter & Dr. Kristin
Wilkins, Dr. Mike & Susan

**Contributors ($50 - $999)**

Allman, Peter & Maureen
Basler, Dr. Rod & Debbie
Beatty, David & Abi
Beynon, Liz
Bringewatt, Elizabeth
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# Our Mission

Today, Barth syndrome is a rarely understood, frequently fatal, genetic disorder primarily affecting males. The Barth Syndrome Foundation is an engaged, global community whose mission is...

***Saving lives through education, advances in treatment, and finding a cure for Barth syndrome.***

Thank you for your generous gifts that made all of this possible. We hope you will continue to support us so that we may continue to offer these vital programs to all the boys and men affected by Barth syndrome.

**Raphael (age 10)**

*(Photo courtesy of Tiffini Allen 2016)*

**"BSF is both as a family, loving, helpful and supporting, and a huge source of information. Even if our son is affected by a rare disease, we never feel alone, and BSF gives us the strength to live with Barth syndrome, and gives us hope that the future of our kids will be brighter."** ~ *Florence, Mother of Raphael, France*

## With your help, we are entering a new threshold of hope — clinical trials!

**BSF Awarded Spot on 2016 Top-Rated List of Nonprofits from GreatNonprofits!**

**"Barth Syndrome Foundation's commitment to advance an awareness and science behind this enigmatic killer makes BSF truly the best nonprofit organization."** ~ *Zaza Khuchua, PhD, Research Associate Professor, Children´s Hospital Medical Center, Cincinnati, OH*

Researcher and clinician attendees at BSF's 2016 conference *(Photo courtesy of Amanda Clark [2016])*

# Thank you for making a difference in the lives of those affected by Barth syndrome.

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